

Building on Strength to Provide Better Healthcare Anytime Anywhere



# eHealth

# - Building on Strength to Provide Better Healthcare Anytime Anywhere

Presented at the eHealth 2005 Conference, Tromsø, Norway 23-24 May 2005

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4	Acknowledgements
5	Forward
6	Introduction
7	Facilitating the Mobility of Patients and Professionals
12	Supporting More Responsive Health Services
16	Improving Access, Quality, Safety and Productivity
20	Building on Strength - Building the Future
22	Building the Future - Meeting the Challenges

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All responsibility for the final text, the opinions it reflects and any errors, remains, of course, with the editor.

### FORWARD

Building on the strength of the eHealth conferences of 2003 and 2004 and in support of the eHealth action plan, this year's conference concentrates on the three central capacities of eHealth:

- · facilitating the mobility of patients and professionals
- · supporting more responsive health services
- · improving access, quality, safety and productivity.

Through this short booklet we introduce each of the three conference themes, looking at the current European state of play in each domain. Each section also includes opinions and commentaries from key European stakeholder groups: the European Health Telematics Association (EHTEL), the Association Internationale de la Mutualité (AIM), the Health on the Net Foundation (HON), the European Public Health Alliance (EPHA), the Standing Committee of European Doctors (CPME) and the European Society for Quality in Health (ESQH).

In the section on facilitating mobility within and between countries — meeting the challenges of increased mobility we consider the right to patient mobility in the European Union and the potential of the European Health Insurance Card to allow seamless delivery of care across and within European borders. We consider also the largely unseen back-office of health services payment and reimbursement and examine the potential of eHealth systems to ensure the smooth running of such systems.

In looking at supporting more responsive health services and creating greater public awareness through better health information we question the role of health information provision from unproven sources via the Internet and ask how best to meet the challenges of quality assurance in this vast and unregulated medium.

We end by considering the role of eHealth in *improving access to and quality of care, patient safety, and productivity.* Reporting on the outcomes of the first European Patient Safety Conference and its Luxemburg Declaration on Patient Safety, we consider the potential of eHealth tools and applications to stem the tide of patient injury through healthcare delivery, and discuss the savings they might provide not only in human pain and suffering but also in public funding.

This collection of comments and opinions is, of course, just a snapshot of eHealth and its many applications. Its aim is to whet the appetite and encourage readers to delve deeper into the challenges ahead and examine more closely the many exciting examples of eHealth already applied in Europe.

The paper ends by looking ahead to the main challenges for building on current European strengths in eHealth in order to realise the huge potential this domain offers for the equitable provision of safe, accessible health services of high quality.

### INTRODUCTION

eHealth is coming of age. It is now more than 40 years since the idea of using information technologies to support the organisation and delivery of health services was first discussed, and we have come a long way since those initial 1960s' ideas about health informatics and bio-medical computing.

A personal computer linked to a secure intranet is now standard issue in almost all doctors' offices. Across Europe the organisation of health services is being changed to make best use of information technology to improve access, quality and productivity in health services delivery.

In the United Kingdom over 90% of general practices now regularly use computers for clinical care¹ while 95% of Norwegian doctors use the Internet professionally². Their counterparts in several new Member States are similarly adopting information and communication technologies.

eHealth is not, however, just about computers on doctors' desks. The term, eHealth, embraces a huge variety of devices, tools, applications and methods of work.

It encompasses a wide range of applications from the simple provision of static health information to citizens over the Internet, to the implantation of devices in the human body in order to capture complex bio-signal data and regulate the functioning of the human body.

eHealth tools play an important role across the continuum of healthcare related activities, from the administration and planning of health services to the execution of surgical procedures.

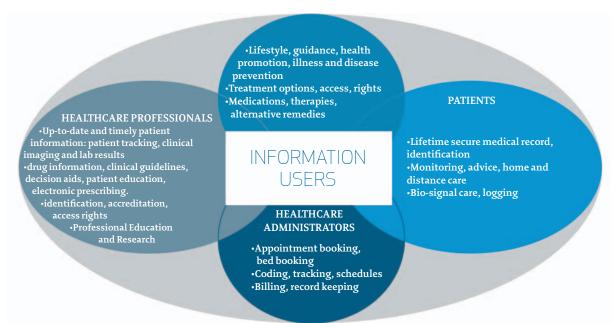
eHealth may be characterised as the tools that can facilitate the processing, sharing and transfer of information and data across the whole spectrum of citizen, patient, health professional and health administration relationships and interactions.

These tools include health information websites, electronic health records, booking systems, digital image capture and sharing systems, bio-data sensors and captors or any other of the vast array of applications that exist. The key factor about eHealth is that it facilitates the interactions not only between diverse parties, but also between the types of information.

If we take the example of a home nurse visiting an elderly patient at home and using a notebook computer with appropriate software and a secure connection she can immediately record data which:

- indicates bio-data such as blood pressure and weight in the appropriate section of the patients medical record
- sends a note to the mental health team co-coordinator to make an assessment
- records prescription of an anxiolytic medication in the medical record
  - delivers an authenticated prescription request to the
- local pharmacy
- records the visit duration in the nurse's employment
- · time-sheet
- adds the visit to the billing data of the administration
- tean

completes and submits the registration documents for the patient to take part in a trial



The graphic indicates just some of the varieties and levels of information available to the users of eHealth systems and services ranging from citizens, to patients, health professionals, and administrators.

<sup>&</sup>lt;sup>1</sup> Department of Health. Delivering 21st century IT support for the NHS: national strategic programme. London: Department of Health, 2002. www.dh.gov.uk/assetRoot/04/06/71/12/04067112.pdf

<sup>&</sup>lt;sup>2</sup> Nylenna and Aasland 2005 – unpublished

# FACILITATING MOBILITY WITHIN AND BETWEEN COUNTRIES - MEETING THE CHAIL ENGES OF INCREASED MOBILITY

#### The state of play

Through its treaties, regulations, directives, legal decisions and guidelines the European Union seeks to enhance four basic freedoms: the freedoms of movement of goods, services, capital and people. Community law provides citizens with rights to seek certain healthcare services in other Member States and be reimbursed. It also provides citizens with entitlements to health care acquired in one Member State to be recognised when they move to another.

The European Court of Justice has clarified the conditions under which patients may be reimbursed for healthcare provided in another Member State than the Member State of affiliation of the patient. The regulation and the court decisions create the following legal framework for patient mobility<sup>3</sup>:

A European citizen temporarily visiting a Member State other than her own for travel, study, posting, or job search who happens to need healthcare is entitled to receive care and reimbursement on the same basis as a person insured in that country.

A European citizen is entitled to seek, and be reimbursed for, any non-hospital care to which she is entitled

in her Member State in any other Member State without prior authorisation of the home state.

A European citizen is also entitled to seek hospital care to which she is entitled in the home Member State in any other Member State provided authorisation has been granted by the home health system.

The legal decisions and regulations provide an important framework of entitlement. The Court judgement of course set only a precedent, they do little to facilitate the practical realisation of treatment across borders. For citizens really to be able to make the best possible use of healthcare available in other countries, they need to seek information about care in other countries and to furnish those providing the care with full and accessible information about their own health status and previous care.

Health care professionals must be able to exchange patient information securely and in confidence and health service administrators must be able to check entitlement to care with ease, security and speed.

# Electronic Health Records and Smart Cards - the key to full patient mobility?

Freedom of movement to obtain health care is not, however, limited to movement between European countries. The need to access specialist care, the pursuit of a second opinion, or a change of location as a result of a house move, may all require a patient to shift from one health-care provider to another. At present many such moves require a patient to re-tell her story,

a health care practitioner to re-record it, and if necessary to undertake repeat tests and investigations to complete the picture.

Currently, patients' health data are often fragmented and stored differently in different organisations across each health service.

In some places patients' histories remain recorded on paper while in others the information may be held electronically. Even where information is held electronically often the systems used for this are not capable of sharing that data with electronic systems used elsewhere. Instead they operate as discrete and stand-alone systems. As a result the patient or service user present at any one point in the system has care delivered without the clinician being able to access instantly the patient records held electronically in another part of the system.

A fully integrated electronic health record system brings with it many benefits – it eliminates the need for repeated history-giving. This boosts the confidence of patients and service users that each and every caregiver is fully informed. Instant accessibility of treatment histories helps to avoid the replication of tests.

An evaluation of the introduction of an integrated care record was recently conducted in one region of the United Kingdom. It was estimated that, in the cases of stroke or diabetes, replications of tests usually occur once per general practitioner per week. If, through anintegrated care record, general practitioners were able to access the details of patients' previous hospital treatment, a smallish city with 100 practicing general practitioners could save on the costs of a total of 15,000 doctors' appointments a year for stroke and diabetes patients alone.<sup>4</sup>

A 2005 study of 817,483 registered patients and 1,179 primary, secondary, and speciality care providers in the north-western region of the United States compared the use of ambulatory care before and after the introduction of electronic health records. There was a general decrease in use of both primary and specialty services, and the percentage of patients making more than three visits a year to a doctor fell. Telephone contacts were made more effective by the immediate availability of patient information, and replaced some outpatient visits.<sup>5</sup>

A key component of freedom of movement between medical practitioners is the availability 24 hours a day, 7 days a week of a 'live' patient record that all health professionals in whatever setting, hospital, primary care or community services can access. Such a record will not, however, do much to enhance the freedom of movement of European citizens seeking healthcare across internal European borders.

Continues on next page...

<sup>&</sup>lt;sup>3</sup> see for example Judgments of the Court of Justice in Cases C-120/95(Kohll) and C-158/96 (Decker); Case C-157/99 (Smits/Peerbooms); Case C-385/99 (Müller-Fauré)

<sup>&</sup>lt;sup>4</sup> Public Value and E-health (July 2004)Institute for Public Policy Research http://www.ippr.org.uk

<sup>&</sup>lt;sup>5</sup>Terhilda Garrido "Effect of electronic health records in ambulatory care: retrospective, serial, cross sectional study" BMJ2005;330:581

Freedom of movement of patients across Europe would be greatly enhanced by easy access to secure and authenticated proof of entitlement and medical records. Thus, the European Commission adopted in 2003 a Communication on the introduction of a European health insurance card. The Communication provides for the gradual adoption of a European Health Insurance Card which will ultimately lead to electronic versions of health care entitlement forms (E111, E121 etc.). These may lead in due course to interoperable record systems that allow verification, not only of a European citizen's entitlement to care in another Member State, but also grant secure access to all or part of her care record to healthcare professionals practicing in another Member State.

The eEurope 2005 action plan paves the way for Member States' use of the European Health Insurance card to promote a common approach to patient identifiers and functions such as the storage of medical emergency data. In addition, the eHealth action plan promotes actively the use of health cards.<sup>7</sup>

The European Health Telematics Association (EHTEL) is a keen supporter of the Electronic Health Record and the system changes it requires. Dr Stephan Schug and Mr Marc Lange of EHTEL recommend that, since patient mobility and borderless health care have received top rankings on the political agenda of Europe health and telecommunications policies, it is now time to acknowledge that these goals are best supported by implementing modern eHealth infrastructures. They argue powerfully that eHealth applications using those infrastructures, such as ePrescribing, electronic referral and discharge letters and – more importantly – networked electronic patient files, will become part of any health and social services in the next few years. At the same time they alert us to the fact that health cards are only a small part of the picture.

European health cards are a key element of the European goals of patient mobility and borderless healthcare. They are not however an end in themselves but rather a component of a total system.

A broad consensus now exists that it is not feasible to store significant quantities of digital health data on cards. Those data should be stored in networked – some say federated – electronic healthcare record systems (EHRS) and be accessible by means of secure "keys", i.e. with identification/authentication means.

Hence it is rather unlikely and undesirable for political and financial reasons that one "Health Card", i.e. a smart card storing personal medical data, could come into use everywhere in the European Union.

This is also in line with the eEurope Action Plans adopted by the European Member States. Those plans foresee binding implementation phases for ICT in healthcare: the "Health On-line" chapter of the eEurope 2002 Action Plan included the objective to establish nationwide health telematic infrastructures as a basis for healthcare. While the eEurope 2005 Action Plan announced the support of a common approach to patient identifiers and electronic health record architecture through standardisation, the current eHealth Action Plan<sup>8</sup> highlights identity management and focuses additionally on interoperability of eHealth infrastructures and services.

Although a single "Health card" is not desirable, the same reasoning does not apply to cards used as a proof of entitlement in another Member State, since an EC Regulation rules this situation. 29 countries (i.e. the Member States of the European Union, those of EFTA and Switzerland) have issued or are in the process of issuing European Health Insurance Cards (EHIC<sup>9</sup>).

Although this is a eye-readable card only, some preliminary steps have already been launched in the direction of an electronic card:

- 10 out of 29 countries are issuing or will issue EHIC on the reverse side of a national or regional card: Czech Republic, Germany, Italy, Luxembourg, Lithuania, Austria, the Netherlands (recommended), Poland, Slovakia, Lichtenstein
- The data which are written on the card are or will be electronically available in 13 countries thanks to:
- A magnetic stripe in Spain and Portugal
- A micro-processor chip in Germany, France, Region of Lombardy (Italy) and Austria
- A database under restricted access in Belgium, France, Ireland, Sweden, Estonia, Poland and Norway.

Taking into account the rather limited perspectives for European "Health Cards", it makes more sense to concentrate on secure keys required for accessing on-line health data and services. Like "a tree hiding the forest", the word "card" could even be hiding the crucial concept of secure services incorporating eldentification, eAuthentication (e.g. for remote access control of health data and services and privacy protection) and eSignature (e.g. for transmitting/updating health data when the professional responsibility is engaged) and recently defined as "Secure IAS Services". 10

This slight change in approach has the advantage of opening the door to a first observation and a first question: if secure IAS services may be provided by various type of cards such as bank cards, health cards or identity cards, therefore, should we consider the interoperability only of cards or of the full IAS services?

By considering secure IAS services, we are not looking at an object, the card, but at an entire system, made up of cards, infrastructure components and a set of services. This inevitably leads us to consider the interoperability question in a global manner.

Member States like Austria and some others have well

<sup>&</sup>lt;sup>6</sup> see Communication from the Commission concerning the introduction of a European health insurance card COM(2003)73

<sup>&</sup>lt;sup>7</sup> see e-Health - making healthcare better for European citizens: An action plan for a European e-Health Area COM(2004)356

see e-Health - making healthcare better for European citizens: An action plan for a European e-Health Area COM(2004)356

 $<sup>{}^{9}\,</sup>More\ details\ on\ the\ EHIC\ web\ site\ at\ http://www.europa.eu.int/comm/employment\_social/healthcard/index\_en.htm$ 

<sup>1</sup>º It has to be noted that "Secure IAS Services" may be provided by using different technologies (PIN Code, biometric, PKI) each of them offering a different level of security and trust.

understood this approach when agreeing upon common specifications for a card offering secure IAS services and leaving stakeholders to take care of issuing health and social security cards, student cards, signature cards, and national identity cards. All these cards are interoperable within their country in the sense that they are using the same infrastructure and offer the same secure IAS services for accessing on-line data and services that citizens seek. Finland goes even a step beyond by deciding to offer the same secure IAS services both on cards and on mobile telephones!

The freedom of movement in healthcare would therefore be better

supported by ensuring interoperability between infrastuctures offering secure IAS services (e.g. by means of electronic identity cards, health cards, any other cards or even by any other device or token).

In theory, two approaches can be considered for ensuring

this interoperability:

- · one common system across Europe.
- different and interoperable cards, infrastructures and secure IAS services.

However, in practice, one basic principle must apply: a common objective and a common legal basis in a diversity of legal and technical environments.

How many countries of the European Economic Area are deploying or have at least politically agreed upon deployment plans for electronic cards for the purposes of eID or Health Insurance/Social Security? 17 countries out of the 29! And 4 more countries are discussing such a deployment plan. Furthermore, other countries which have no plans for smart card deployment, like Norway and Denmark, do have plans or are deploying IAS services using vehicles other than cards.

	BELGIUM	CZECH REP.	DENMARK	GERMANY	ESTONIA	GREECE	SPAIN	FRANCE	IRELAND	ITALY	CYPRUS	LATVIA	LITHUANIA	LUXEMBOURG	HUNGARY	MALTA	THE NETHERLANDS	AUSTRIA	POLAND	PORTUGAL	SLOVENIA	SLOVAKIA	SWEDEN	FINLAND	UNITED KINGDOM	SWITZERLAND	ICELAND	LICHTENSTEIN	NORWAY	
FULL DEPLOYMENT				•	•		•	•		•								•			•		•	•						10
DONE OR ONGOING	Ī	l				L			L	ļ		l				L				l					l	l	<u>.                                    </u>	J	L	
PILOT OR PLANS																														7
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PLANS UNDER DISCUSSION																				•		•			•	•				4
NO PLAN FOR	1	]					[ -				]				[ - <u>-</u>									Ī -	Ī ·	]	]	[		6
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 $Deployment\ of\ eID\ or\ Health\ Insurance/Social\ Security\ cards\ in\ Europe$ 

Not all these cards are offering secure IAS services, but it is now a fact that infrastructure components are or will soon be deployed in the field. It is now the right time to consider implementing the necessary platform for making them interoperable.

Implementing cross-border interoperability should be done in stepwise approach, linking each step with a clear political statement and tangible benefits for the users i.e. both the citizens and the health professionals. These steps could for instance be the following:

- Interoperability in using administrative data, because no citizen should be prevented from travelling within the EU because he/she needs or may need health care during his/her temporary stay.
- Interoperability of a basic set of health data and secure IAS services for citizens, because no citizen should be prevented from travelling within the EU because local health practitioners need or may need to access emergency data or other electronic health records during any stay abroad;
- 3. Interoperability of IAS services for health professionals, because any cross-border cooperation between health

care providers and the provision of borderless health care rely on the existence of mutually or better globally accepted health professional cards.

One key final question however remains: Are the citizens ready for such a interoperability? The reports gathered together in this document underline the readiness of the health sector to meet the challenge. On that basis, just six months after the launch of the EHIC card in 14 Member States, more than 16 millions of interoperable European cards are in circulation. A further five Member States will start distributing the European card by summer 2005. One can expect that by that time not far from 50 million EHICs will be in the pockets of citizens in case they need health care abroad. This figure might even double by summer 2006.

On the basis of numbers alone it would seem then that European eHealth interoperability is on its way and is becoming a reality for more and more citizens. The EHIC is of course only the beginning, but nevertheless an important beginning of eHealth as a key tool in enhancing European patient mobility.

#### Marc Lange and Stephan H Schug

EHTEL (European Health Telematics Association)

If we accept the argument that cards are a vital part of the complete eHealth picture, it is important to ask also what role eHealth might play in the wider administration of health systems. Lange and Schug have demonstrated well that because health services delivery depends on the secure accessibility of a wide range of data, the health card is key to creating a larger federated system. The more applied question then arises: does eHealth have a role to play in the back-office of health services administration?

This question is addressed from the perspective of the Association Internationale de la Mutualité, which argues that the payment systems it uses will have important interfaces with eHealth.

Most Western Europeans do not have to pay directly when they visit a doctor, or when they need surgery. Some do have to pay but are reimbursed later; some pay only a small proportion of the cost. Arranging the payments and reimbursements to which people are entitled involves a huge 'back-office' operation that is in some health systems run by State health schemes, in others by big mutual health funds or various health insurers. Sometimes two such institutions can be involved in every health treatment: the money can come from two places, or even three if the patient must contribute too. To operate in this way, paying agents of all kinds need their own huge installed infrastructures to handle data capture, networking and computing. At their opposite ends, these infrastructures have to interface with the medical world and with the financial world.

Furthermore, the health finance systems in different European countries can be completely different. The European Union treaties themselves do not intend eventual harmonisation of health financing or delivery. These differences affect not just local (regional or national) infrastructures and institutions - they also affect the principles of payment. Thus, the e-systems for the paying agents have to be different too. Given that diversity, there seems no obvious prospect of building networks or back-office systems which can benefit from European scale.

In an increasing number of countries, paying agents are also becoming involved in activities beyond simple 'reimbursement': pre-authorisation of treatment, endorsement of clinical protocols, or monitoring of quality and outcomes. They do this to reconcile the quality of healthcare provision that people need with the ever-spiralling costs of health care.

Clinical decisions are properly to be taken by doctors. However, many paying agencies are now encouraging more transparency about the cost implications of the choices made. So there needs to be better integration during diagnosis, treatment and follow-up. If paying agencies introduce acceptable systems, providers (who like to be paid) will want to use them.

European patient mobility will become an important influence, as patients may increasingly be entitled to treatment across borders. Cross-border reimbursements may double the number of agencies involved in financial arrangements, and can cause conflicts of rules. Even when systems succeed in automating local entitlement and reimbursement rules, the local schemes or contract conditions can often be changed, both in detail and in principle. Not all countries will have or want to have electronic cards, and the new (non-electronic) E111 card only gives evidence of the person's 'social security' system entitlements. Networks and portals will nevertheless increasingly need to interoperate in an environment of complexity and change.

So where should the big mutual health funds, and paying agents in general, look for e-health-business help and solutions for their sector? Even if the system diversity is not likely to be reduced, at least they can, together, build 'architectures' that generalise some of that diversity. Then, they can explore technically what 'common objects' might exist among the different systems and which 'properties' of those objects are relevant to each system.

In the worldwide (non-health) insurance sector, much progress has long since been made using such principles, described as 'object orientation' - which the Organisation for the Advancement of Structured Information (OASIS) coordinates for business". To apply that kind of analysis to the specificities of European health entitlement and reimbursement, two OASIS-linked subgroups within the eBusiness Board for European Standardisation (eBES)¹² are developing a repository of newly defined common 'objects' and data-definitions for health insurance.

Ultimately, perhaps these 'objects' can be 'called off' over a network, directly by the web-based language XML so that enquiries can be automated and differences of data definition accommodated. Local 'methods' specific to a one- or two- country transaction can thus be applied so that the patient's experience will be straightforward, even if there are many conflicts of rules still to be resolved inside the system. Using the same networks, paying agents can look forward to enhanced interoperability, if and when they need it – between countries, and between systems within a country. Software vendors could perhaps find scale-opportunities to develop value-added services serving the diversity of European health systems.

Paying agents are routine users of coding systems. They use them typically for identity, entity, clinical procedures, diseases and sometimes diagnoses. These coding systems

<sup>&</sup>quot; Organisation for the Advancement of Structured Information Standards www.oasis-open.com

<sup>12</sup> eBES has expert groups, called 7 and 9, that focus on insurance and health respectively

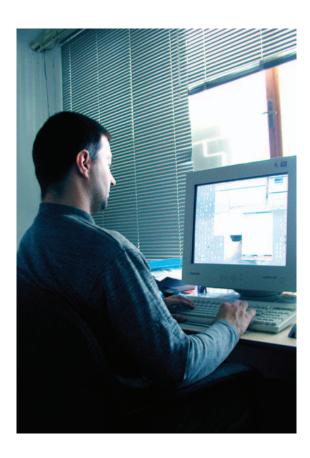
can be as diverse as the national health systems themselves. Even apparently similar code sets may not map together because of local implementation differences. In the interests of interoperability, it may become useful to register and align the code sets in use - a European Standard is available to do this. Several institutions seem to want to help with registration but for paying-agencies the first priority must be to get the underlying 'object' model for 'entitlement and reimbursement' established via the 'eBES' groups. Where the coding systems are primarily for clinical use (and only secondarily used for payment) the aim would simply be mutual recognition, because here clinical utility should prevail, in the patient's interest.

Much excellent work has been done by clinicians and relevant experts on 'clinical' architectures, for example, in the Health Care Informatics Committee of the European Standards authority (CEN) and its counterpart in the International Standards Organisation (ISO). However, paying agents have not been involved or consulted in these matters in Europe, nor generally would they need to be. All paying agents ask is that the clinical experts should deliver timely, available, practical specifications, which can be reliably interfaced if that is necessary and permissible. Conversely, paying agents would not want groups which were set up to establish clinical informatics and which have no other formal mandate, to get involved in the specifics of entitlement and reimbursement. As the need for common data standards in the paying agency sector grows, it is likely that 'eBES' channels will be used instead to establish requirements and methodologies for this sector.

So, are insurers' needs really part of eHealth? The answer lies ultimately in the definition of eHealth.

If eHealth is used in its clinical sense to cover the diversity of clinical applications, then the answer would be 'no', because mutual health funds mostly aim to pay for services rather than provide the services themselves. If however eHealth is taken in its sense of the use of information technologies in healthcare, then all paying agencies (and most especially the mutual health funds with their traditional focus on their members' more general wellbeing) would have a strategic interest in any innovations, like eHealth, that could better preserve and repair health, encourage mobility, and empower patients. Mutual health funds will welcome such clinical efficiencies as may derive from eHealth and willhope that the cost benefits of these technologies will either bring overall prices down or at least help moderate clinical cost increases for their subscribers

#### Association Internationale de la Mutualité



# SUPPORTING MORE RESPONSIVE HEALTH SERVICES AND CREATING GREATER PUBLIC AWARENESS THROUGH BETTER HEALTH INFORMATION

Information is a vital part of our daily lives. We use it to make decisions ranging from the most important questions in our lives to mundane daily choices. Whether specifically about health (or not), information provides the basis of all our decision-making, contributes to the perception and management of personal choices and therefore has a significant impact on our individual health.

Several recent surveys have been undertaken of how many people use health related websites, and how. A recent nation-wide American survey, conducted in February 2004, provides a snapshot of the numbers of people using the Internet to find answers to health related questions. It found that 74% of Internet users, or 111 million people, in the United States (that is, 51% of all adults), had gone online in search of health information<sup>13</sup>. A Eurobarometer survey of March 2003 found that 41% of the population of the then 15-state European Union believed that the Internet is a good source of health-related information. Access to good health information is important for all European citizens. So, the European Commission adopted in 2001 a Communication which sets out the key quality criteria for health-related websites. The objective of the Communication was to guide Member States in the implementation of quality assurance measures for health-related information on the Internet. It is a unique document that simultaneously tells suppliers how to comply with key quality criteria while it educates users with regard to what quality of information they ought to expect from a good health website.

On the basis of the eEurope 2005 Action Plan the Member States of the European Union have agreed to develop initiatives to enhance the quality of health information available to citizens. They have adopted strategies to implement the six core quality criteria: agreed as a result of consultation with key European actors and stakeholders. These core criteria are transparency, authority, privacy, accountability, currency, and accessibility.

**Transparency** - of purpose and objective of the site (including any commercial purposes) and of sources of funding for site (grants, sponsors, advertisers, non-profit, voluntary assistance).

**Authority** - statement of sources for all information provided and date of publication of source, name and credentials of all human/institutional providers of information put up on the site.

**Privacy** - security and confidentiality policy and systems clearly defined.

**Accountability** - user feedback, and appropriate oversight responsibility, responsible partnering or linking to other websites. Clear editorial policy on procedure used for selection of content.

**Currency** - clear and regular updating of the site.

**Accessibility** - physical accessibility as well as general findability and readability.

<sup>&</sup>lt;sup>13</sup> Harris Interactive Health report April 2004

Further initiatives are now underway in Europe to establish the possible adoption of European-level quality assurance symbols that will mark selected health-related websites as trustworthy. One such example is currently in development by the Health on the Net Foundation, winners of one of the 2004 eEurope Awards for eHealth awards<sup>14</sup>.

The Internet is still changing rapidly, more than ten years after its birth. Growth continues in the number of web pages available and in every category of Internet use. The use of quality labels and quality criteria has been extensive, as different groups have responded to the sudden proliferation of new information sources.

Over the past decade, one such scheme – the HONcode, has enjoyed widespread success. Initiated by Health on the Net Foundation, an international non-governmental organisation based in Geneva, the HONcode is an educational tool that promotes ethical publishing standards to an audience of some 4,800 accredited web publishers.

Although the HONcode is the only standard to have been widely adopted, other quality accreditation programmes have been realized. AFGIS (aktionsforum gesundheits -informationssystem)15 is dedicated to German-language health web sites. URAC (Utilization Review Accreditation Commission), in the United States, is an industryled initiative with several dozen members enrolled in a voluntary programme. These efforts have all addressed the need for standards in online consumer health publishing. However, the search for quality in health-related information on websites is not met entirely by voluntary labelling schemes. According to HON's annual survey of Consumer Health Internet Use (held online from 3rd November 2004 to 31st March 2005 with 2012 respondents16), awareness of health web site quality labels is far from universal, with the most widely recognised (HONcode) known to only 51% of respondents.

The time has come to find more powerful, automated means which can be used to sift through the vast number of health web pages now online. Currently available quality rating schemes face important challenges. They are limited by the need for human reviewers. Voluntary programmes may be unable to attract all the best participants, while those based on a selection process will inevitably miss some excellent resources. Raising public awareness about the existence of any specific scheme means competing for the famously short attention spans of Internet users.

The quality standards promulgated by public or private entities are meant to be inclusive. Compliance requires disclosure, which is not a barrier to any applicant acting in good faith. Providers of health information and promoters of health products are required to back up claims of performance and provide scientific references to substantiate their claims. However, the standards requirements in their current form are not always sufficient to exclude a publisher of misleading information or an entrepreneur who believes fervently in a useless product.

A publicly administered quality programme will need to be transparent and provide recourse for rejected applicants. International trade agreements could be invoked to protect commercial expression that does not actually violate the law. Conversely, the legitimacy conferred by a quality label could result in legal action being taken against the issuing authority if it can be shown that the information source was not thoroughly vetted.

HON survey results show that government-sponsored accreditation may not enjoy the same degree of public confidence as that granted by an educational or medical institution. Government oversight of the Internet left nearly half (43.4%) of respondents indifferent or negative, while trust was highest for web sites sponsored by Universities (89.4%) or Medical Journals (88.9%).

As any experienced Internet user can attest, even the most powerful general-purpose search engines are increasingly less successful at delivering quality results. To the credit of their designers, these applications have scaled well to accommodate billions of documents, but often fail to identify the best sources. The health domain is unlike any other online knowledge domain. The accuracy and reliability of information is crucial.

Patients and other non-specialists need to be guided through a technical environment fraught with risk. One promising solution lies with specialised search engines, offering access to vetted information sources. Trustworthy information is an absolute necessity if we are to supply eHealth to improve health equitably to all citizens.

Recognising this need and building on the experience of voluntary quality labelling Health on the Net Foundation has pioneered a new generation of automated quality analysis tools. This began with the European Union-funded research project Worldwide Reliable Advice to Patients and Individuals (WRAPIN). This new quality tool targets a restricted knowledge domain (health/medicine) and analyses the substantive content of online documents.

The application is made workable by a restricted-domain concept, which enables the use of controlled vocabularies and draws on ontological and semantic analysis. The system identifies key concepts and attempts to synthesise a conclusion, checking the scientific references for corroboration.

These technical solutions ensure that citizens are empowered with knowledge and tools that enable them to make educated health-related decisions. Thus, they not only enhance their personal knowledge of their own health status, but also ultimately participate actively in improving their own health and, collectively, that of their community and society.

#### Celia Boyer

Health on the Net Foundation

<sup>14</sup> see Awards website - http://www.e-europeawards.org/

<sup>&</sup>lt;sup>15</sup>The Health Information System Action Forum, agis e.V., is a registered association under German law. It is a forum for the quality assurance of health information in new media like the Internet.

http://www.hon.ch/Survey/Survey2004/questA.html

Using eHealth to make a health service more responsive does not end with giving citizens better access to better information. Health information is more than Websites.

Responsiveness is also about collecting information so as to make better health planning decisions or to assist patients in managing their own health and health decisions better. The potential for accessible, readable and well ordered medical records to assist in planning has been recognised for some time – indeed, as long ago as 1863, Florence Nightingale commented in her Notes on Hospitals<sup>17</sup>:

I am fain to sum up with an urgent appeal for adopting ... some uniform system of publishing the statistical records of hospitals. There is a growing conviction that in all hospitals, even in those which are best conducted, there is a great and unnecessary waste of life ... In attempting to arrive at the truth, I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purposes of comparison ...

If wisely used, these improved statistics would tell us more of the relative value of particular operations and modes of treatment than we have means of ascertaining at present."

The potential of electronic health records to meet such needs is clear. But offering simple records of medical encounters and procedures is not all that eHealth can offer. The use of a standardised Electronic Health Record would allow data collection and aggregation at a level of complexity and security that Florence Nightingale could only have dreamed of. While it is of course paramount that patient confidentiality is maintained at all times it is possible to use the data gathered and stored routinely in patient records to feed databases at national, regional and supra-regional level which will allow the development of European responses to European level problems. Computer scientists are currently exploring the potential of Grid super computing technology to allow the linking of national data banks in order to undertake truly European level epidemiological research.18

New developments beyond simple records include wearable captors and sensors, which can record biomedical data directly from the body and transfer the information into records and databases for interpretation by healthcare professionals.

Such an application is currently being pioneered in a research project co-funded under the European Union's 6th Framework Programme. The MyHeart'9 project is developing a series of applications and devices that support individual citizens to maintain their cardiovascular health. This happens by making choices which are good

for cardiovascular health: physical activity, good nutrition, beneficial sleep, and stress management.

The wearable devices use captors to record vital signs like heart rate, and breathing rate for determining activity levels including the assessment of the user's fitness condition. In turn, these data provide feedback to the user on current rates of activity and motivation to reach optimum targets of activity. Other sensors record sleep patterns; they include tools for diagnosing sleep quality related diseases, like depression, which is a frequent complication for post myocardial infarction patients. To prevent the risk of myocardial infarction, captors can be worn to detect ischaemic events. If such an event is recorded, an immediate alarm can be sent via mobile or fixed networks to an emergency service. The early diagnosis of these events limits irreversible damage to the heart muscle, by reducing time to treatment to less than one hour.

But are we entering into a brave new world as a result of the introduction of such devices? Are we opening ourselves up to 'big brother' surveillance and invasions of privacy?

Tamsin Rose, from the European Public Health Alliance, argues that the availability of health information to all and the development of new eHealth tools creates many new possibilities but also raises the question – can the promise of eHealth be fulfilled?

The importance of information is rightly underlined: our modern world cannot function without it. This synergy is particularly visible in terms of health, where information can often determine our collective or individual well-being.

The challenge for eHealth lies fundamentally in the human element. Experience from the environmental sector on behaviour patterns on recycling, energy saving and purchasing patterns have clearly demonstrated that 'information in- action out' is often not a linear equation.

Across the developed world the statistics are similar in the health sector. Only about 50 % of people follow their treatment regimes for chronic diseases. This can have serious consequences for individual health and healthcare costs. Studies have shown the inconsistency of our perceptions, knowledge and behaviour about health issues. Consumers regularly under-report consumption of unhealthy foods, and smokers understand the health risk for other smokers but perceive themselves to be at lower risk. Despite widespread knowledge about condoms protecting against sexually transmitted disease, individuals indulge in risky sexual behaviour.

<sup>17</sup> Florence Nightingale, Notes on Hospitals

<sup>18</sup> A White Paper for Health Grid http://whitepaper.healthgrid.org

<sup>19</sup> see http://www.hitech-projects.com/euprojects/myheart/

There is certainly great potential for eHealth tools across a range of platforms (Internet, mobile phones, television, and monitoring tools) to provide tailored information when it is needed. For example, reminders about medication and precise home measurements of blood pressure or insulin level, could improve compliance with treatment regimes. Individualised food advice and support could improve healthy eating patterns.

But even the most sophisticated technology system relies on human interaction and this is a significant potential weakness for eHealth. People take out the batteries in their smoke-detectors, write down or give out their computer passwords or banking personal identification number, and store harmful products where children can reach them. After spending money on consumer items such as mobile phones, video recorders and computers, few people invest the time to read the operating manual that explains all of the functions that they have bought.

At a fundamental level, eHealth is about the relationship between the organic and the technological. Health is a very personal issue connected to our sense of self and individual identity. It is rooted to our beliefs, community values, and traditions. Loss of control or independence through ill health can be a great fear. During much of human history, the power to heal was linked to spiritual or supernatural powers. Healers, shaman, medicine men and women were the holders of secret arcane knowledge and believed to receive divine inspiration.

It is only during the last few hundred years that health has become more of a science rather than an art. It can provide answers with evidence on what is wrong with us and how ill health can be fixed. As people have become accustomed to this system of cause and effect, questions of responsibility and blame have increasingly arisen.

When medical science fails to provide an answer, public reaction is often driven by fear or superstition. Loss of confidence in medicine and technology can be swift and devastating. For example, safety concerns about child-hood vaccinations have slashed immunisation levels in the United Kingdom in particular and reduced population protection against common scourges such as measles.

This, therefore, is the context for eHealth. As societies, we invest great hope in the possibility of science and technology to cure illnesses and extend life. In most science fiction scenarios, two opposing trends can be detected.

The optimistic visions provide an end to disease, pain and suffering. Popular television series show detailed scans (non-invasive of course!) that identify ill health very early on and indicate interventions at the cellular or genetic level that immediately rectify problems. For proponents of this viewpoint, technology becomes the tool that delivers benefits, and that is integrated with our bodies in a synergistic and routine manner. Artificial organs and nano-technology freshened blood could keep us in optimal condition. Some scenarios take the challenge even further: our minds would no longer be enslaved by the

frailty of the human body as evolution takes humanity to new levels of existence.

The more apocalyptic approaches see the gradual loss of humanity in the face of growing automation and even a take-over by machines. In these visions, small groups of renegade 'naturals' fight against mechanised monsters, which might be augmented humans or intelligent machines. As any campaigner for road safety will attest, when flesh and metal collide the conclusion is usually foregone.

Another deep suspicion is that the technology could act as a tool of an authoritarian, dictatorial state to monitor, control and track all individuals. Perhaps the most infamous example is George Orwell's book 1984 in which 'big brother' invades every aspect of life including dreams. The hero fights for the right to independent thought and embraces life through sexual freedom.

Concerns expressed about existing technologies are that implanted chips may provide vital medical history but could also spell the end of privacy. A full genetic blueprint of each individual could lead to new forms of discrimination.

What this means for eHealth is that new technologies will not automatically be embraced despite potential health gains. New procedures or devices will need a more general acceptance in society. For example, while organ transplantation has become routine, the use of genetically modified materials from animals or plants has not. Genuine efforts need to be made by scientists, governments, health authorities, and commercial companies, to understand and respect religious or ethical concerns, particularly about the integrity of the human organism.

The end-users of a device may be frightened, in pain and have compromised sensory awareness. Demographic changes mean that many eHealth users will be very elderly, so simplicity and ease of use of products and services must be over-riding concerns at the concept stage. The eHealth devices and systems put in place need to be robust enough to deal with inappropriate or inconsistent use and strike a balance between allowing individual choices while the individuals themselves are not fully reliant on them.

Technology does not exist in isolation. It must be fully embedded in the realities and norms of society. It is in this way that the promise of eHealth can be fulfilled.

#### Tamsin Rose

European Public Health Alliance

# IMPROVING ACCESS TO AND QUALITY OF CARE, PATIENT SAFETY, AND PRODUCTIVITY

Across the European Union the delivery of healthcare shares three key features: it consumes a significant amount of costly human resources, it carries significant safety risks for patients and staff, and it is information-intensive.

In many sectors healthcare delivery remains highly fragmented and lacks efficiency. eHealth therefore holds great potential – its core power lies in handling and storing vast amounts of information and uniting that information across a wide diversity of settings.

Many studies have been conducted to examine the potential of eHealth tools to contribute to efficiency gains in health care. A 2003 American survey examined a pilot community data network which created a tool for exchange of health care data among physicians, hospitals, insurers, and others in the community. The study showed that using the pilot network improved the quality and reduced the cost of health care. On completion the pilot is expected to achieve over \$US7 million in benefits for participating organisations. Other expected benefits include fewer admissions to the emergency department, reductions in staff time spent handling test results, and avoidance of test duplication.<sup>20</sup>

Another recently published report of the use of electronic health records in the United States within hospitals in two regions with a total population of 817,523 reported that two years after electronic health records were fully implemented, visits to general practitioners fell by 11% in both regions. They showed also that the percentage of insured persons making more than 3 visits a year decreased by 10-11% while the percentage making fewer than 2 visits a year increased. Intermediate measures of quality of health care remained unchanged or improved slightly. Based on these findings the researchers concluded that readily available, comprehensive, integrated clinical information reduced use of ambulatory care while maintaining quality and allowed doctors to replace some office visits with telephone contacts. Shifting patterns of use suggest reduced numbers of ambulatory care visits that are inappropriate or marginally productive.21

Similarly, in England in March 2005, at the Good Hope hospital, Sutton Coldfield, a team using workflow software to plan clinical procedures, found that it had cut the cost of treating leg ulcers by 26%. If these figures are extrapolated across the United Kingdom, they would add up to £150 million in savings a year. The scheme was so effective it was selected as winner of the UK Health IT effectiveness awards.<sup>22</sup>

# The Ultimate Challenge: Containing Costs but Improving Safety and Quality

While cost-containment remains a dominant challenge for many health service providers, patient safety is becoming an equal contender for a priority position.

It is well known that patients die from poor prescribing. In 2003, according to the United States Agency for Healthcare Research and Quality, adverse drug events caused 777,000 injuries and deaths a year.<sup>23</sup>

Lisette Tiddens, Secretary General of the Standing Committee of European Doctors, reports on the first European Patient Safety Conference held under the Luxembourg Presidency of the European Union in April 2005. She argues that eHealth has the capacity to contribute significantly to improved patient safety, and urges everyone working in a health service to make patient safety the top issue on the eHealth agenda.

"Access to high quality care is a key human right recognized and valued by the European Union, its Institutions and the citizens of Europe." With these words, the Luxembourg Declaration on Patient Safety adopted during the first European Patient Safety conference, the European Union made a clear commitment to patient safety.

The Luxembourg Declaration is the outcome of a two-day conference that initiated more widespread political attention to patient safety. In the Declaration, patient safety is recognised as an issue to be treated not only at European level but also at national and local levels.

The Luxembourg conference drew the analogy between healthcare and high-tech and high-risk industries, in particular military aviation, by stating "The health sector is a high-risk area because adverse events, arising from treatment rather than disease, can lead to death, serious damage, complications and patient suffering. Although many hospitals and healthcare settings have procedures in place to ensure patient safety, the health care sector still lags behind other industries and services that have introduced systematic safety processes." Indeed, whereas most of these high-tech and high-risk industries make thorough use of systems that safeguard quality and prevent adverse outcomes, the healthcare sector still relies on chance and imperfect humans rather than on solid, thought-out structures, contingency plans and fail-safe mechanisms.

Health care professionals are humans and medicine is not always an exact science! Adverse events do occur. This reality needs to be acknowledged by all parties involved in order to improve quality of care through optimising safety. In this much-needed system review, tools must be created to help reduce the number of adverse events and thus contribute to the quality of care all over the European Union. In this systematic approach, eHealth can play an important role.

The role of the European Union is not of course to tell Member States how to run their hospitals. Rather, as a supra-national structure, the European Union's added value comes through such initiatives and instruments as studies, framework approaches, and exchange of experi-

<sup>&</sup>lt;sup>20</sup> Report to the Ranking Minority Member, Committee on Health, Education, Labor, and Pensions, U.S. Senate INFORMATION TECHNOLOGY Benefits Realized for Selected Health Care Functions October 2003

<sup>&</sup>lt;sup>21</sup> Effect of electronic health records in ambulatory care: retrospective, serial, cross sectional study Terhilda Garrido, Laura Jamieson, Yvonne Zhou, Andrew Wiesenthal, Louise Liang BMJ2005;330:581 (12 March)

<sup>&</sup>lt;sup>22</sup> see http://healthcare-computing.co.uk/hitea/index.html

<sup>&</sup>lt;sup>23</sup> Ball MJ. Leveraging IT to Improve Patient Safety. Yearbook of Medical Informatics of the International Medical Informatics Association (IMIA). 2003

ences and good practices. Although it is likely that nations will start taking action only when confronted by their own evidence, it is also highly probable that solutions in one country will be applicable to another. The role of the European Union is therefore as a facilitator, enabling regions and countries to benefit from the exchange of results obtained in a specific locality, no matter how small or remote. A 2004 Commission Communication focuses on this open method of coordination<sup>24</sup>, and the exchange of good practice is strongly taken up in the eHealth Action Plan.<sup>25</sup>

Europe can also play a crucial role in creating the conditions necessary to enable a culture of patient safety. Healthcare professionals are encouraged to report adverse events, near misses and close calls in an environment that clearly benefits all actors concerned, thanks to mutually accepted values and guidelines. Through such openness we can move from a culture of shame and blame (based on litigation, liability, and guilt) to one of learning, understanding and improvement. The shift from compartmentalised, sectoral methods to a comprehensive, multi-disciplinary, system-wide approach involving all stakeholders and all levels of policy-making is highly beneficial.

The Luxembourg Declaration recommends to the European Union and national institutions to harness the power of the eHealth knowledge bases in order to develop and implement eHealth tools, thus addressing patient safety more actively. A selection of the tools includes:

- Establishing a European Union solution bank with best practice examples and standards.
- Optimising the use of eHealth technologies such his improvement would include personal medical profile and decision-making support programmes for health professionals, with a view to reducing medication errors and increasing compliance rates.
- Protecting privacy and confidentiality of electronic patient records and ensuring that the relevant patient information is readily available to health care professionals.

- Establishing a culture of patient safety throughout the entire health system. The adoption of such an approach by many players and institutions, and the potential evidence gathered, makes it clear that this is the first step that needs to be taken.
- Introducing risk management as a routine instrument
  within the running of the entire European health sector. A precondition for risk management is an open and
  trusting working environment with a culture that focuses on learning from near-misses and adverse events
  as opposed to concentrating on 'blame and shame' and
  subsequent punishment. A good example of such a
  routine instrument would be to develop guidelines and
  indicators as a part of an accreditation system for quality assessment in the health care sector.

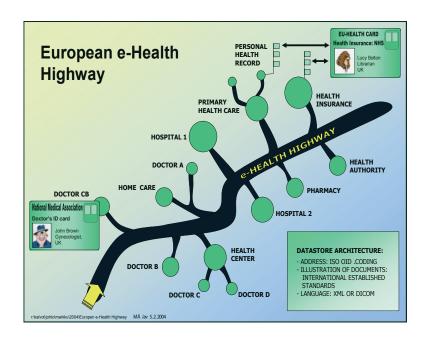
The illustration of the European eHealth Highway that follows shows just how such a highway could look, and thus how the information required could accompany a patient who is transferred from a general practitioner to a specialist or who is travelling from one hospital or country to another hospital or country.

In such a structure, it is the system that delivers the basis for good quality care. Transparency, which can also guarantee the protection of privacy, optimises and secures the patient care and clarifies the roles of all the players involved.

The proposed system can be completed with the use of both a patient card that could contain insurance data, such as those available on the health insurance card that came into effect in 2004 but that could also have more personal data included. Or it could take place via a card designed for health professionals. A health professional data card could be used both as a professional identification card and could allow access to patient data when these are required.

#### Lisette Tiddens

Standing Conference of European Doctors (CPME)



<sup>&</sup>lt;sup>24</sup> Modernising social protection for the development of high-quality, accessible and sustainable health care and long-term care: support for the national strategies using the "open method of coordination COM (2004) 0304

<sup>&</sup>lt;sup>25</sup> e-Health - making healthcare better for European citizens: An action plan for a European e-Health Area COM(2004)356

The European Patient Safety Conference noted the role of decision support in enhancing patient safety and recognised that eHealth can reduce errors created by poor medical prescribing.

Electronic prescribing is not a simple stand-alone tool. It should be part of a more complex eHealth system, which would allow a number of electronic tools to work together to enhance patient safety and quality of care. An accessible electronic patient record, complete with patient history, allergies and sensitivities can make traditional forms of prescribing much safer.

Sophisticated decision support tools – which support information and assistance concerning drug administration – and clinical decision guidelines for medication safety (drug interaction, allergy checking, detecting adverse drug events) reduce errors during routine procedures.

A recently published meta-analysis of 71 studies evaluating the efficacy of decision support systems. The studies involved about 6,000 clinicians, who acted as study subjects while they continued to care for about 130,000 patients. The meta-analysis found that overall 48 of the 71 (68%) decision support systems significantly improved clinical practice. <sup>26</sup>

Commenting on the potential of eHealth tools to enhance quality in health care, Benno van Beek of the European Society for Quality in Healthcare notes in particular the importance of evidence based systems on which decision support and other eHealth tools may be built.

Recent developments in healthcare are changing the way in which healthcare professionals deliver care and these new methods are having a positive effect on the quality of care from a patient's perspective.

One of the basic tools on which healthcare professionals – in particular doctors – rely while treating patients is medical guidelines. The way such guidelines are developed is changing. These shifts are described in the following table:

Informal consensus	$\rightarrow$	Evidence based
Monodisciplinary	$\rightarrow$	Multidisciplinary
Paper versions	$\rightarrow$	Electronic versions
Limited life expectancy	$\rightarrow$	'Living guideline'
Focus on development	$\rightarrow$	Focus on implementation

Today's trend is to make guidelines more evidence-based and more patient-oriented by reducing the time to develop them. The time involved has been reduced from a period of two years and an evaluation after five years, to a twice-yearly judgement on the up-to-date status of the guideline Still many questions remain unanswered, such as:

- how to design the authorisation procedure?
- how to judge whether updating of guidelines is necessary?
- how to organise the updating in a structured way?
- what IT support is necessary?

For the healthcare professional, answering these questions, by using a decision support system and in consultation with patients, can become an exercise in shared decision-making. The process acts as a first step towards improving the communication between the patient and healthcare professional.

Another way in which information and communication technologies can enable a more patient-centred approach is through the delivery of patient questionnaires and patient satisfaction surveys. These feedback tools are already used often, but can be optimised through minor technological improvements, as illustrated in the table below:

THE WAY IT WAS	THE WAY IT SHOULD BE
Abstract information gathered on a high level; i.e. 60% of patients are dissatisfied with waiting time in our hospital.	Gather relevant information for care deliverers on relevant level of aggregation; i.e. the average waiting time for patients visiting a neurology department is 14.7 minutes.
Discontinuous measurement.	Continuous measurement.
Measuring satisfaction; i.e. how satisfied were you with the information received?	Measuring actual experiences; i.e. did you receive adequate information about how to use your medication?
Separate measurements by patients and professionals; double costs and twice as many patients needed.	Integrate professional expertise and disease specific knowledge in combined measurements.
Lots of money and time needed for data input.	Automatic input by patients through the Internet, and hos- pital 'information pillars'.

By thinking along these lines a far more effective dialogue can be developed and a much more valuable benchmarking exercise established.

<sup>&</sup>lt;sup>26</sup> Improving clinical practice using clinical decision support systems: a systematic review of trials to identify features critical to success Kensaku Kawamoto, Caitlin A Houlihan, E Andrew Balas, David F Lobach, BMJ 2005;330:765 (2 April),

On a more demographic note, it is important to realise that Europe is faced with a rapidly growing number of elderly people due to current shifts in population. As we grow older, and more and more people live to the ripe old ages of either over eighty and ninety, the amount of care required will grow substantially. In particular there will be a wide impact of age-related diseases, ranging from diabetes to neurodegenerative complications. The fact that two-thirds of healthcare costs in life are incurred in the age bracket over 65 years old, ensures that we quickly understand the severe burden facing the diverse health care systems in Europe.

Some countries have begun to seek ways to solve this problem through market-oriented approaches, looking at how competition can help to keep their systems sustainable. Indeed, competition and economy are all around us. As consumers, we are faced daily with questions about what to buy and what not to buy. As we become more healthcare dependent in the later stages of our lives, we are likely to want to stay independent as long as possible. Is it therefore unusual to expect that we should become more and more confident with the prospect of health selfmanagement or that we become the managers of our own healthcare? This process can only take place through the use of proper mechanisms and tools, most of which will rely on information and communication technologies.

An interesting epidemiological development in the Netherlands and the Dutch-speaking part of Belgium was the way in which the annual flu epidemic was monitored during autumn 2004 and winter 2005. A number of universities and other research institutes joined forces to set up a web site that tracks the annual flu epidemic that reaches some 10% of population (www.degrotegriepmeting.nl). Tens of thousands of people registered themselves on this site. They were requested to submit their flu symptoms through a short questionnaire once a week so as to track the course of their health and flu developments. The site is updated every hour.

This website is one of an increasing number of applications of new technologies that involves citizens/patients in a new way. The potential improvement of quality of care is based on more information, different ways of communicating and patient feedback that should hopefully become more commonplace in the near (bright?) future than is the case today.

#### Benno van Beek

European Society for Quality in Healthcare



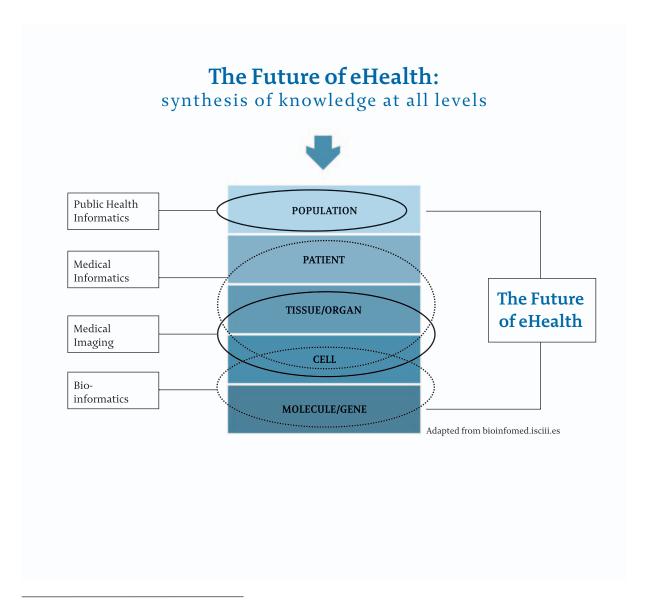
## BUILDING ON STRENGTH - BUILDING THE FUTURE

The systems and services described in the preceding pages have shown that Europe has strength in eHealth. The challenge is now to look ahead and build on current European strengths in eHealth in order to realise the huge potential this domain offers for the equitable provision of safe, accessible health services of high quality.

We are beginning to adopt integrated health records, which in turn can populate epidemiological bases, which in their turn support the building of decision support systems, and which facilitate and make safer the delivery of healthcare across Europe. The discussions have shown that across the range, from the simple electronic E111 form to integrated decision support systems based on data collected from the patients via wearable bio-sensors, all eHealth applications are dependent on one common factor: data.

Data acquired from the interactions patients have with their health care providers may extend across a huge array of information types. They may include environmental data when, for example, a doctor notes rising pollen counts in the need to prescribe anti-histamines. They may include social data noting, for example, work related stress in the treatment of anxiety. The data in a health record will necessarily include clinical data from a physical examination, as well as data recording facts at tissue, cell or even genetic level as a result of laboratory testing and medical imaging.

It is the synthesis of all these types of data that are considered to form the current – and particularly the future – orientation of eHealth. This synthesis and collation of diverse levels of heterogeneous data will be accessed by many sorts of users through very large databases, including Grid-based applications.<sup>27</sup>



 $<sup>^{\</sup>scriptscriptstyle 27}\, Health GRID - A\, joint\, White\, Paper\, from\, the\, Health grid\, Association\, and\, Cisco\, Systems\, www.health grid.org$ 

#### **COMPUTING GRID**

For data crunching operations

An environment, created through sharing heterogeneous and dispersed health data eg:

Population (epidemology)

Personal data (health records)

Tissue data (cancer types)

Cellular data (pathways)

Molecular data (genomics, proteomics)

in applications accessed by all users as an tailored information providing system according to their authorisation and withouth loss of informations

### DATA GRID

Distributed and optimised storage of large amounts of of accessible data

### KNOWLEDGE GRID

Intelligent use of Data Grid for knowledge creation and tools provisions to all users

Adapted from DG Information Society and Media, European Commission

## BUILDING THE FUTURE - MEETING THE CHALLENGES

The collection of opinions and ideas expressed in this report has been about showing the potential of eHealth to become a key tool in the better provision of health services. We have sought to show that, from the back-office of health services administration to decision support in the operating theatre, eHealth can make a difference. In the words of the European Commission's eHealth Action Plan, we have sought to show that "eHealth matters. It can improve access to healthcare and boost the quality and effectiveness of the services offered."

We do not offer any solutions here, but seek to leave you with food for thought in setting out some of the commonly agreed needs which must be addressed in order to make the most of eHealth investment and some of the barriers which are commonly perceived to be blocking its full implementation in the delivery of health services.

## eHEALTH NEEDS:

- **Proper Investment** it is generally accepted that 5% of all health investment should be devoted to eHealth infrastructure and change management if the full potential of eHealth is to be realised.
- Full Interoperability there is little point in making large investments if the information systems that are developed cannot communicate with each other. In order to reap the benefits of eHealth across all health services and across the EU we must develop and adopt common standards which allow health professionals to work together.
- Adaptation of Legal and Regulatory Responses in order for eHealth systems to be fully integrated the existing legal framework must be adapted to fit the new tools. There is, for example, little point in having a secure electronic prescription system if, as is still the case in many EU countries, a prescription has to be submitted on a specified form. Similarly access to patient data rules has to be adapted to ensure that Grid technologies are useable while ensuring that patient confidentiality and security of data are maintained. These legal and regulatory issues are matters of considerable public concern, and need to be addressed in a straightforward and cooperative way.
- Systematic User Involvement applications must minimise impact on workflow and provide additional value. Early involvement of the system users, from the grassroots level to the boardroom level, will enable development of systems which all those using health information systems actually want to use. Systematic user involvement must be continuous from inception to in-service evaluation.
- Integrated and Responsive Change Management in order to make the most of eHealth not only is user involvement crucial, but also proper change management. This should address not only the possibilities but also the fears associated with eHealth, such as changes to professional work habits and concerns about differences in workloads.





Sosial- og helsedirektoratet







